

March 10, 2015

Cara Johnson Tarricone

North Windham, CT

Subject : HB 6862

I would like to thank the Public Health Committee for its time and devotion, and for realizing the true need to make pediatric cannabis available in our amazing State of Connecticut.

Our daughter, West Ann Tarricone, twin to Blake Augustino Tarricone, suffers from severely disabling epilepsy. The first seizures came when West was 10 months old. At 11 months of age, West was diagnosed with West Syndrome. Just as West was emerging in childhood, epilepsy took her from us. As Blake grew and mastered milestones, West struggled.

In her short life, West has taken over 14 pharmaceutical medications and tried palliative treatments, several of which nearly killed her. Daily, West also relies on two different rescue drugs, which we carry with us always; Even a 4-minute trip to Blake's bus stop requires that we be prepared to rescue West's life with emergency medication in the event that she stops breathing or experiences other physical failures during acute seizures.

West has 1000's of seizures a day: myoclonics, absence, tonic and tonic clonics. None of the pharmaceutical drugs she was prescribed offers a cure for her epilepsy. And, symptom reduction isn't a fixed relief, as it doesn't allow West to live free of epilepsy for periods of time that benefit her growth. Even with pharmaceutical intervention, West still requires daily "one-to-one" at school, to keep track of her seizures and to provide for vast developmental needs caused by her seizures. Additionally, the school West attends maintains two licensed nurses on staff who administer rescue medications for West when necessary. Because of West's epilepsy, nothing can be left to chance with regard to her day, whether the seizures themselves or the residual environmental risks accompanying them, and this is while she takes presently available, prescribed drugs.

West has "tried it all," medically speaking. It is time she have safe access—with her doctor's approval—to receive prescription cannabis. With this medically safe treatment, West's cognition can improve as her seizures can be dramatically reduced. And, with the correct cannabis rescue medication, West can stop taking heavy doses of valiums and benzos, which further traumatize her body. While present medications can reduce a grand mal (aka tonic clonic) that normally lasts 17-20 minutes, and while present medications can reduce the seizures escalation, it does not make seizures "go away." BUT, with a proper medical cannabis rescue prescription our child could not only stop seizing quickly, they could "go away." West could get back to living her life; she could have a much different life. Potentially, West could experience the same milestones her brother, Blake, has experienced.

As a parent I have researched and studied epilepsy, present pharmaceuticals for epilepsy, and medical

cannabis. I have listened to fellow parents of children with epilepsy, who suffer from debilitating seizures, who moved like refugees to states that allow medical cannabis. What I found are amazing stories of success, and formerly debilitated children living invigorated lives. I've heard of many children smiling for the first time, saying "Mommy" and "Daddy" and talking, walking and drawing, expressing emotions such as joy and sadness. I have seen changes in other people's children ALL because of cannabis. I know families that are now medication-free and their child(ren) are seizure-free. I know this is possible for children in our state. I know this is possible for my daughter, West.

I appreciate and applaud you for committing to study medical cannabis as an option for epilepsy in children. And, I implore you to look at neighboring states and their successes with pediatric cannabis. Elsewhere, cannabis is medication. Cannabis is an accepted, safe medication. Let's make it legal here, now.

Our children need medical cannabis now, in our home state. Before this study is approved, our children could die during severe seizures or from complications during seizures. Cannabis has successfully eliminated seizures in children, and it is safely being used by pediatrics in states where it is presently legal. Let us be another safe state. Until it's approved at the federal level, please pass a state law that allows Connecticut residents to find treatment for our children in our home state, so we might not find ourselves refugees in other states with already-accepted progressive medical legislation.

We support Bill 1064. We need action now; our children cannot wait. Please trust in doctors, parents, and growers to work as teams, to make these medical decisions.